



# Transcending Borders for Better Health

*Empowering the Future Through Research, Education, and Care*

## About the Consortium

The Ireland-Northern Ireland-National Cancer Institute Cancer Consortium (or All-Ireland NCI Cancer Consortium) is focused on endeavours that encompass all aspects of cancer control on the island of Ireland. Its members work collectively to fund initiatives that can make a broad impact and this cooperation enables improved scientific programmes in each jurisdiction—Ireland, Northern Ireland, and the United States—in the following areas: research (including biobanks); education and training for physicians, nurses, and scientists; interactions aimed at enhanced public health and patient care; diagnosis and treatment; epidemiology (including registry and surveillance); quality assurance; palliative care and survivorship; prevention and early detection.

## Impact of Cancer on the Island of Ireland: A Shared Challenge

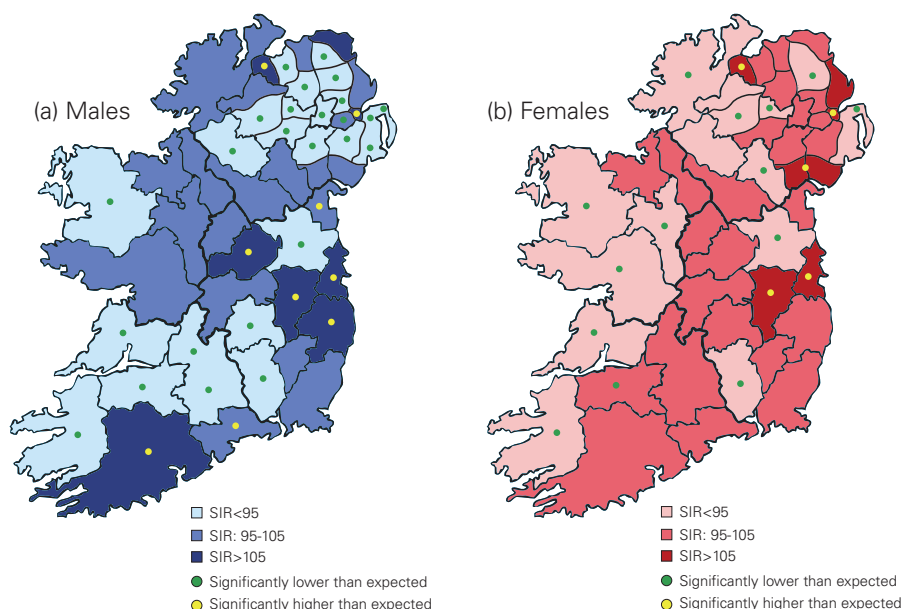
*“The number of newly diagnosed cancers in Ireland is increasing by 6-7% every year, making the Consortium’s goal of reducing the incidence of and mortality from cancer in Ireland extremely relevant.” (Dr. Tony Holohan, Chief Medical Officer, Department of Health and Children, Ireland; Consortium Board of Directors, 2009 Chair)*

On the island of Ireland, cancer is the most common cause of death, accounting for one quarter of all deaths between 2001 and 2004. Incidence of cancer increased over the 10-year period beginning in 1994, with an annual increase of 584.5 cases each year.

The fight against cancer on the island of Ireland faces many challenges in the years ahead. Despite different models of funding and provision for medical services,

the similarities in cancer patterns between Ireland and Northern Ireland generally outweigh the differences. On the island, the most rapidly changing factor affecting cancer levels is the changing population size and age distribution. Between 1994 and 2004, the overall population rose by 10.0% with an increase in the percentage aged 60 and above (15.8% to 16.2%), and a decrease in the percentage aged 15 to 24 (24.7% to 20.9%). These demographic trends will continue into the future and will place a substantial burden on the health services of Northern Ireland and Ireland as one in every three persons will develop a cancer by the time he or she reaches 75 years of age.

Significant differences in county/council standardised incidence rates (SIR) for all cancers (excluding NMSC) compared to Ireland as a whole: 1994-2004



Source: Donnelley DW, Gavin AT, Comber H. 1994-2004: A Comprehensive Report. Northern Ireland Cancer Registry/National Cancer Registry, Ireland; 2009.

*The Third All-Ireland Cancer Statistics Report*—a joint effort of the Consortium and the cancer registries of Ireland and Northern Ireland—provides more information on the impact of cancer on the island: [www.allirelandnci.com/publications/statistics\\_third\\_report.shtml](http://www.allirelandnci.com/publications/statistics_third_report.shtml).

*“The launch of the Third All-Ireland Cancer Report was the culmination of three years of collaborative work and provides us with an excellent reference volume on cancer incidence, treatment, and survival on the island of Ireland.” (Dr. Anna Gavin, Director, Northern Ireland Cancer Registry; Chair of Consortium’s Cancer Registries and Epidemiology Working Group)*



## The Consortium in Action

*“We have gained experience and knowledge from ICORG beyond that of the trials themselves, which have allowed us to build our capacity and efficiency in clinical trials for our current and future patients with cancer.”*

Dr. Michael McBride, Chief Medical Officer  
Department of Health, Social Services and Public Safety, Northern Ireland  
Consortium Board of Directors (2010 Chair)

### Streamlining Collaborative Research and Care: TELESYNERGY®

*“The TELESYNERGY® System helps us to bring together a range of clinical experts...it has enhanced the care of thousands of cancer patients in Ireland since 2000.”* (Donal Hollywood, Professor of Clinical Oncology, Head of the Academic Unit of Clinical and Molecular Oncology, Trinity College Dublin)

The TELESYNERGY® System is a multimedia medical imaging workstation that has enabled the Consortium to enhance collaboration among its partners in all three jurisdictions and advance its goals in diagnosis and treatment. It combines cameras, microscopes, audio equipment, and a variety of peripheral devices to allow scientists across the globe to work together as if they were standing side-by-side. A similar version of the system without the radiation therapy functionality (TELESYNERGY® Lite) has also been installed into some regional hospitals.

Over the past decade, 10 state-of-the-art TELESYNERGY® workstations have been installed across the island of Ireland, making joint consultations, advanced training, and participation in off-site research possible.

### Enabling Clinical Trials: All-Ireland Cooperative Oncology Research Group

*“Ireland is now in a strong position to contribute actively to research that results in better outcomes for cancer patients in Ireland and worldwide. Thousands of patients in Ireland have directly benefited from access to the latest trials.”* (Dr. Anne Cody, Head of Research Infrastructure and Special Initiatives Unit, Health Research Board)

The Consortium and its partners established the All-Ireland Cooperative Oncology Research Group (ICORG) to strengthen the capacity for cancer centres on the island of Ireland to conduct cancer clinical trials. ICORG is a not-for-profit registered charity funded by a grant from the Health Research Board and the Health and Social Care Research and Development Division, with support from the Irish Cancer Society.

In its first 10 years, ICORG expanded to a network of 14 hospitals, opened 71 research protocols, and enabled 3,500 cancer patients on the island of Ireland to access cutting-edge treatments previously only available in the United States and elsewhere in Europe.

### Education and Training

*“Since 2001, the National Cancer Institute has trained over 300 scholars from the island of Ireland; an impressive accomplishment that makes our efforts in education and training one of the Consortium’s greatest success stories.”* (Isabel V. Otero, M.P.H., International Program Director, Office of International Affairs, NCI; All-Ireland NCI Cancer Consortium Director)

The Consortium recognizes that an important component of improving the state of cancer control and research on the island of Ireland long-term is the building of a capable workforce with the skills and knowledge necessary to practise cancer control. The Scholar Exchange and Training Working Group was established to address the need for a more highly-trained cadre of cancer professionals on the island of Ireland. Consortium-endorsed scholars are exposed to challenging coursework, networking opportunities, hands-on training on the island of Ireland and in the United States, and other methods to enhance their knowledge of cancer topics and to develop relationships across borders.





### Number of Scholars supported by the Consortium (2000-2010)

Type of Exchange Programme	Duration of Programme	Participants by Jurisdiction			Total Participants
		Ireland	Northern Ireland	United States	
Epidemiology Fellowship	3 years	2	1	1	4
NCI Clinical Trials Training for Nurses	3 weeks/3 months	11	9		20
Clinical Trials E-learning Module for Nurses	12 weeks	23	17		40
Health Economics Fellowship in Cancer <sup>^</sup>	4 years	5	1		6
NCI Summer Curriculum in Cancer Prevention: Molecular Prevention Course	1 week	117	38		155*
NCI Summer Curriculum in Cancer Prevention: Principles and Practice of Cancer Prevention and Control Course	4 weeks	79	36		115*
NCI Cancer Prevention Fellowship Program	4 years	3	4		7
Joint Research Projects in Cancer (JRPC)	2-3 years	8*	5	8	21

\* The total number of participants includes fellows who completed the course as a requirement for the NCI CPFP, JRPC, and HRB/NCI Health Economics Fellowships in Cancer.

\* The number of Irish participants includes Irish fellows who completed Joint Research Fellowships in Cancer.

<sup>^</sup> This is a joint programme between the Health Research Board, Health and Social Care Research and Development Division, and the National Cancer Institute.

### 2009 Consortium Accomplishments

- Published Third All-Ireland Cancer Statistics Report
- Conducted four TELESYNERGY® meetings
- Hosted the 2nd Health Economics Workshop at the Dublin City Library and Archive—attracting more than 70 academic researchers, students, clinicians, and government officials
- Sponsored two new fellows for the HRB NCI Health Economics Fellowship in Cancer Program
- Published *Recommendations for the Establishment of a National Cancer Biobank*
- Hosted the Tracy's Kids International Art Exchange at the St. James's Hospital

- in Dublin and Our Lady's Children's Hospital, Crumlin
- Accrued almost 1,500 patients to All-Ireland Cooperative Oncology Research Group studies
- Held a public symposium at the Institute of Molecular Medicine St. James's Hospital and Trinity College Dublin called, *The Fight Against Cancer: Where Do We Stand?*—attracting more than 100 participants
- Hosted 40 cancer care research leaders in Antrim, Northern Ireland, for the Cancer Care Research Workshop
- Funded six Joint Research Projects in Cancer in Ireland and Northern Ireland

- Funded 15 All-Ireland participants in the NCI Summer Curriculum in Cancer Prevention
- Hosted the *Cancer 2009: International Cancer Conference* at the Institute of Molecular Medicine, St. James's Hospital and Trinity College Dublin. More than 200 delegates from the island of Ireland participated and NCI faculty were featured as speakers
- Coordinated the Conference on Population-Based Cancer Research—the first conference of its kind in Ireland—which took place in Dublin and had more than 145 attendees
- Selected St. Vincent's University Hospital Dublin and the Mater Misericordiae University Hospital Dublin as the final installation sites for TELESYNERGY® Lite



## Consortium Quick Facts

### Consortium Origins

- Conceptualized by cancer physicians in the three jurisdictions, who took their idea for a collaborative partnership to their respective governments
- Established in October 1999 with the signing of a Memorandum of Understanding (MOU) by the health ministers of Ireland and Northern Ireland and the secretary for the U.S. Department of Health and Human Services
- Renewed in November 2006 with the signing of a revised MOU by the health ministers of Ireland and Northern Ireland and the secretary for the U.S. Department of Health and Human Services, to include collaboration in scholar exchange, nursing, information technology, cancer

registries and epidemiology, clinical trials, prevention, biobanking initiatives, health economics and cancer policy analysis, and palliative care

### Governance Structure

- Governed by a Board of Directors (BOD) consisting of the chief medical officers of Ireland and Northern Ireland, who rotate board chairmanship annually, and the Director of the U.S. National Cancer Institute. The BOD is guided by requirements of the MOU.
- A Strategic Advisory Group has been appointed by the BOD to make recommendations on initiatives and programs. Membership includes the chief nursing officers of Ireland and Northern Ireland;

representatives of the Health Research Board in Ireland, the Health and Social Care Research and Development Division in Northern Ireland, and the National Cancer Institute; and clinicians, basic scientists, prevention specialists, and cancer registry officials from across the island of Ireland and the United States.

- Ad hoc Working Groups and Interest Groups conduct activities tied to the specific Consortium initiatives identified in the 2006 MOU. The current Working Groups include: Cancer Registries and Epidemiology, Clinical Trials, Information Technology, Nursing, Prevention, and Scholar Exchange and Training. Current Interest Groups include Biobanking and Palliative Care.

### Consortium Partners

Ireland	Northern Ireland	United States
 <p>Department of Health and Children <a href="http://www.dohc.ie/">http://www.dohc.ie/</a></p>	 <p>Department of Health, Social Services and Public Safety <a href="http://www.dhsspsni.gov.uk/">http://www.dhsspsni.gov.uk/</a></p>	 <p>Department of Health and Human Services <a href="http://www.dhhs.gov/">http://www.dhhs.gov/</a></p>
 <p>Health Research Board <a href="http://www.hrb.ie/">http://www.hrb.ie/</a></p>	 <p>Public Health Agency Health and Social Care Research and Development Division <a href="http://www.publichealth.hscni.net/">http://www.publichealth.hscni.net/</a></p>	 <p>National Cancer Institute <a href="http://www.cancer.gov/">http://www.cancer.gov/</a></p>
		 <p>Office of International Affairs <a href="http://oia.cancer.gov/">http://oia.cancer.gov/</a></p>

### For more information

Isabel V. Otero, Consortium Director  
isotero@mail.nih.gov or +1.301.435.4434